

# Challenges, Successes, and Issues: the Texas MS Surveillance Experience

Judy Henry

Texas Department of Health

March 24, 2004

EPHT Conference



# Project Staff and Collaborators

## TDH

Laurie Wagner \*

Jeff Shire, MS

## Texas Tech University

Randolph Schiffer, MD

Kelly Beasley, RN

## ATSDR

Dee Williamson, ABD

Curtis Noonan, PhD

Mary White, PhD

## El Paso MS Community

Lubbock Neurology  
Community

# Overview

---

- **Background**
  - El Paso Cluster
  - MS Pilot Surveillance
- **Challenges**
- **Successes**
- **Issues**

# Background: El Paso Cluster

- **typical cluster call**
  - too much MS
  - environmental concern (metals smelter)
- **atypical investigation**
  - retrospective cohort
- **results**
  - Do we have an excess of MS?
  - How much of an excess?

# SMR<sub>s</sub>

- 1981 NINDS Survey

SMR = 2.80 (95% CI = 1.52 – 4.66)

- 1989 – 1994 NHIS Surveys

SMR = 1.93 (95% CI = 1.06 – 3.24)

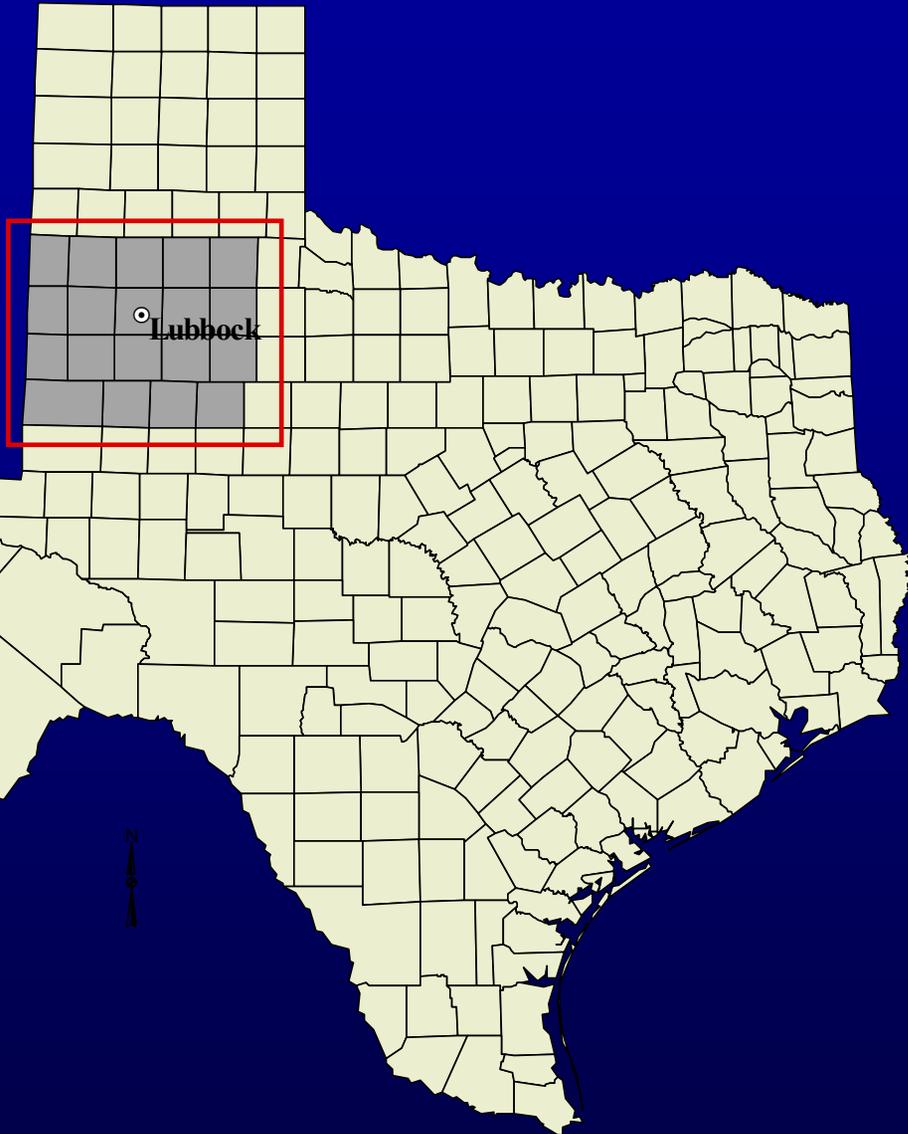
- 1990 Olmsted County

SMR = 1.05 (95% CI = 0.57 – 1.76)

# Conclusions and Recommendations

- **two-fold increased risk of MS**
- **minimum disease burden in cohort (conservative estimate)**
- **develop current MS prevalence estimates for Texas**
- **re-analyze the El Paso cluster**

Bailey	Lamb	Hale	Floyd	Motley
Cochran	Hockley	Lubbock ⊙	Crosby	Dickens
Yoakum	Terry	Lynn	Garza	Kent
Gaines	Dawson	Borden	Scurry	



# Background : Surveillance Area

- **Panhandle - South Plains: 19 counties**
- **17,000 square miles**
- **420,488 people**
  - 58% Anglo
  - 35% Hispanic
  - 6% African-American
- **Lubbock, single metropolitan area**
- **eight practicing neurologists**
- **“captured” population**

# Pilot Results:

→ **prevalence estimate**

42.8 / 100,000

→ **new El Paso SMR**

3.42 (1.87 – 5.4)

# CHALLENGES

---

1. **IRBs**
2. **Neurology Community**
3. **Medical Records**
4. **Bureaucracy**

# Challenges: IRBs

- ⊗ multiple IRBs, different rules, timeliness, etc., etc., etc.
- ⊗ TDH IRB prohibited direct contact with MS patients
  - ⊗ precluded direct use of MS patient advocacy groups

# Challenges: Neurology Community

- ☒ **Surveillance? Who me?**
- ☒ **Getting past the front doors**
- ☒ **Patient / clinical focus**
- ☒ **Governmental phobias**

# Practical Notes:

- **be nice to the surveillance source and appeal to their altruism**
- **be ready to threaten them with any law, rule, or regulation you have**
- **maintain flexibility**

# Challenges: Medical Records

↪ **Pulling records**

↪ **Reading the writing**

↪ **Missing information**

↪ **race/ethnicity for 30%**

# Practical Notes:

1. **Abstracting team**
2. **Abstracting**
3. **QA/QC**

# Challenges: Bureaucracy

---

# SUCCESSSES

---

- ✓ **Laurie Wagner**
- ✓ **Great team**
- ✓ **100% participation of the neurology community**
- ✓ **Legal authority**
- ✓ **Mission accomplished**
- ✓ **ATSDR**

# ISSUES

- ❖ **What do we really need?**
- ❖ **Federal leadership**
- ❖ **Clear goals and long-term commitment**
- ❖ **Coordinated state and federal efforts**
- ❖ **Funding, funding, funding**

# Practical Notes:

---

**Do we really need to be second guessing a neurologist's diagnosis?**

# Multiple Sclerosis

---

**“MS remains a mysterious disease with no known pathogen or even known determinants of its severity or course.”**

*Multiple Sclerosis: Current Status and Strategies for the Future (IOM, 2001)*

Many, many thanks to  
ATSDR for their  
leadership and for  
funding this project.